Reflections on Citizens’ Juries: the case of the Citizens’ Jury on genetic testing for common disorders

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Introduction
Citizens’ Juries are a relatively innovative way of involving ordinary members of the public in decision-making processes. Participants in Wales’ first Citizen Jury reflect on their experiences and some observers give their view about Citizens’ Juries as a method of involving the public in policy making.

Introduction
A Citizens’ Jury on Genetic Testing for Common Disorders in the NHS was conducted by the Welsh Institute for Health and Social Care (WIHSC) in Wales in November 1997. It was the first Welsh Citizens’ Jury ever held and the first public consultation exercise in the UK on the often controversial topic of genetics. The purpose of this paper is to bring together a plurality of views of the people involved in the Jury in order to take forward the debate on ways of better involving the public in decision making.

Those involved in the Citizens’ Jury process include the jurors, the witnesses, the moderator, observers who attended the proceedings and people who commented on the final report of the Jury. This Citizens’ Jury experiment, including a summary of the Jury’s recommendations, have been described previously in this journal and will only be briefly summarised here.¹

The Jury met for a period of four days in November 1997, during which they listened to expert evidence on the question; engaged in group discussions and small group deliberations and, with the assistance of a moderator, devised a set of recommendations about genetic testing for common disorders in the NHS.²

Fifteen jurors were independently recruited to participate in the exercise. Although not a statistical sample, they were broadly typical of the Welsh population in terms of age, sex, social class, education, employment status, marital status and ability to speak Welsh. The witnesses they questioned represented a wide range of opinion on genetic testing and health care, and perspectives
were given from clinical genetics, NHS management, sociology, the private sector, patients and policy makers. By making use of closed circuit television WIHSC was able to invite observers to view proceedings. During the four days approximately 75 people came to observe, and many of these filled out short questionnaires expressing their opinions on the topic and the process.

After the Citizens' Jury the recommendations were presented by several Jurors to the Human Genetics Advisory Commission at one of their meetings in London in December 1997. In March 1998 the Citizens’ Jury report was circulated to a large number of individuals and organisations in the UK and elsewhere. The intention was to target key decision-making bodies and those who may be thinking about genetics and healthcare in the future, including Health Authorities, Trusts, Community Health Councils, Royal Colleges and patient organisations. Approximately 300 copies of the report were sent out and all of these bodies were asked to respond formally to the Jury’s recommendations and to comment on the method of public involvement used.

This paper discusses the perspectives of many of these involved in the Citizens’ Jury process, including the Jurors, the witnesses, the moderator, observers at the event and those who commented formally on the Jury report after it had been sent out for consultation.

The Jurors

Jurors were issued with two sets of questionnaires; one set before and one set after the Citizens’ Jury. The first set were used by WIHSC to gauge how Jurors felt generally about genetic advances before and after the exercise. The second set were issued by the independent researchers contracted by WIHSC to evaluate the entire process. As they were a captive set of respondents the response rate was 100% in all cases. Many of the questions on the pre- and post-Jury questionnaires were the same in order to see how opinions, attitudes and levels of knowledge might have changed as a result of participating in the process.

Before the Jury most of the Jurors considered themselves to be about average in terms of their knowledge about genetics and its impact; after the Jury 14 Jurors rated themselves as more informed than average. Table 1 summarises the change in pre- and post-Jury knowledge.

Most Jurors did not consider themselves to have any particular expertise in genetics beforehand, but almost every Juror found the process educational and informative. Jurors were also asked to think about their feelings towards genetics in the future. Before the Jury there was a mixed range of feelings about genetics, but after the Jury, when asked to think about the future, all 15 Jurors stated that they were optimistic about genetics (Table 2). It is likely that an increased level of awareness about genetics led to a less cautious approach to the subject.

The vast majority of Jurors felt that they had understood the information given by all the witnesses, with only one reporting that the material was fairly difficult to understand. Similarly, they all felt that they understood more about the question as the Jury progressed, and they all reported understanding the issues involved either well or very well. In general, the Jurors felt that there was both fairness and balance in the way the issues were presented, but the absence of discussion on religious issues was noted by some of the Jurors.

From the evaluator’s questionnaires it is clear that all the Jurors found the experience of being on the Citizens’ Jury fulfilling to a greater or lesser extent, albeit intense and tiring. They would all serve as Jurors again and found meeting new people, a greater knowledge of genetics and a general interest in public involvement the main reasons why they would do so.
Table 1 How would you rate your knowledge of genetics and its impact?

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<thead>
<tr>
<th></th>
<th>Before Jury</th>
<th>After Jury</th>
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<tbody>
<tr>
<td>More informed than average</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>About average</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Less informed than average</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2 When you think about genetics in the future are you generally optimistic, pessimistic or neutral?

<table>
<thead>
<tr>
<th></th>
<th>Before Jury</th>
<th>After Jury</th>
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<tbody>
<tr>
<td>Optimistic</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Pessimistic</td>
<td>2</td>
<td>0</td>
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<tr>
<td>Don’t know</td>
<td>3</td>
<td>0</td>
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Reflections of a Juror

Prior to being asked to become a member of the Jury, my knowledge and understanding of genetics was very scant. But after being assured that this was the ideal profile needed, I felt that I was embarking on a valuable and important exercise - not just for myself but for the development of the National Health Service in the UK.

This became even more apparent following the introductory afternoon. I now knew that the recommendations the Jury were to make would be presented to the relevant bodies that advise the Health Service and that I had to approach this in a serious manner and to listen carefully to all the witnesses. I felt that important decisions being made in the UK were for the first time going to take into consideration the concerns and hopes of the citizens. I felt proud to be one of the Jurors.

Having an experienced moderator was vital to the process and his role meant that not only the Jury but also the Witnesses were continually focused on the issue. The whole process from beginning to end was structured so that all members of the Jury could easily partake in the discussions, daily increasing their knowledge, and were given adequate time to assimilate it all prior to coming to a conclusion.

We were given good information about genetics. We considered the consequences as advantages or disadvantages and we came to a decision by identifying peoples’ hopes and concerns. Finally we identified conditions to alleviate or eliminate concerns.

My level of knowledge of genetics is now extremely high and I can easily follow reports and discussions in the media. In fact, I feel that my knowledge and understanding of genetics is on par with many members of the Health Service and probably higher than many politicians involved in deciding the future role of genetics in the UK.

The highlight of my participation on the Jury was the presentation of the Report to the Human Genetics Advisory Commission in London and the knowledge that this Commission responded favourably to the recommendations. I look forward to the future where Citizens’ Juries will consider other important matters affecting the lives of the citizens of the UK.
The Witnesses
For this Jury each witness was briefed face-to-face by a member of WIHSC in the month prior to the Jury taking place. During this briefing the nature of the process was explained and witnesses were asked specifically to keep their presentations short and simple and to avoid jargon. Experience with other Citizens’ Juries in England and elsewhere has shown that the longer the witness talks the more likely he or she is to slip into ‘conference mode’ while the Jurors doze off. Short presentations followed by question and answer sessions made the process more interactive and enabled the Jurors to contrast each witnesses’ evidence with that of other witnesses, as well as to check it against their own personal experiences.

According to the independent evaluators, almost all witnesses had been conscious of the need to try and avoid making assumptions about the extent of prior knowledge amongst Jurors. In spite of this, most witnesses found it difficult to get over the information they wanted to the Jury - but this was largely due to time constraints. In general, the witnesses spoke favourably about the concept of a Citizens’ Jury for exploring a complex issue over a period of time. They were of the opinion that the Jury method offered reasonable value for money and all but one witness said they would agree to participate in a Citizens’ Jury again.

The Moderator
Previous Citizens’ Juries have often made use of two moderators together. There are advantages and disadvantages of this approach. On the one hand, a single moderator has more control over the process and can steer it in any direction he or she wishes to take. On the other hand, given that Citizens’ Juries involve four full days, two moderators share the burden of the work. The Steering Committee made the decision to have just one moderator and in hindsight this was probably the right decision, given the individual involved. Other Juries might be aided by the presence of two individuals. A brief look at how WIHSC’s moderator viewed the experience is described below.

Reflections of the Moderator
I was intrigued to be asked by WIHSC to act as moderator for the first Citizens’ Jury held in Wales. I assumed they invited me because of my 30 years experience of facilitating and enabling authorities and management and professional teams in health and social services consider complex issues, come to decisions and agree strategies and policies. In the event that experience was invaluable; but my learning curve was vertical.

How could fifteen members of the ‘ordinary public’ possibly cope with the complexities of genetic testing? Would they cut through all the technical and clinical jargon and be able to understand the critical issues? Would they be capable of discussing and debating the possible social consequences? Could they maintain enough concentration and energy to come to clear conclusions? Would they be willing to listen to each other, learn from each other and find a way of deciding together? Most people who observed the process: professional experts, knowledgeable observers and visitors, research staff, third part evaluators and not least myself as moderator, were impressed by the way the Jury coped with the task and came up with decisions and recommendations that the Human Genetics Advisory Commission deemed to be valuable.

So what did I learn from moderating the process of the Jury? First I learnt, yet again, that it is easy to underestimate and undervalue the capabilities of people - especially those we have categorised or stereotyped. Granted, the Jury were generally ‘less well educated’ than the average public authority and management team, but they started off not very different from ‘lay’ members of such groups who have to take ‘policy decisions’ in areas that are new or foreign to them. At the start of their
decision process they also do not usually understand all the issues, jargon, clinical niceties, cost options and social consequences of the topic at hand. Indeed, even experienced professional people in the groups do not always grasp all the real issues in parallel or professional areas different from their own.

So it was interesting and valuable to see fifteen citizens - ‘ordinary members of the public’ - with a minimum of help in questioning, learning, considering, analysing, debating and deciding (the group processes), cope with a very complex task. It would have been even more interesting, had we dared, to see how a typical authority or management team handled the same process. So this leads me to my second learning point. The Citizens’ Jury not only affords an alternative method of consultation on, and advice about, policy decision making; it could offer the possibility of a ‘parallel decision process’ - not only consultation but comparison. If the primary decision takers on any social policy issue had the courage to find out how a group of ‘ordinary citizens’ would decide the issue, given the same kind of information, they could then use the outcome as data of a new and qualitatively different kind to inform their own ‘real’ decision taking.

Having observed many different groups consider and come to decisions about similar major issues, I am convinced that a group can learn at least as much from comparisons of their decision processes as from receiving, and then having to handle even more ‘partial’ data than they have already. Of course, this would need to be tested in practice. One way to test it would be for public authorities and management teams who have to decide ‘social policy’ to develop the use of Citizens’ Juries, not just to supplement their other consultative processes, but to provide them with the ‘parallel decision’ data we have suggested. It could have the potential of improving their decision-making along what might be a new dimension.

The Observers
The most immediate impact that the Citizens’ Jury had was on the people who came to watch some or all of the exercise. Approximately 75 people viewed the Citizens’ Jury at some stage over the four days. These observers ranged from civil servants to health service managers and from health and social care practitioners to local schoolchildren. A total of 50 observers filled out a short questionnaire which asked them for their opinions on the proceedings. The results are interesting, given their first-hand experience of the Jury, and their own varied backgrounds.

The questionnaire contained a mixture of closed and open-ended questions. Although the questionnaire covered such issues as organisation, administration, the hotel and the use of CCTV to observe proceedings, what follows is a brief analysis of some of the key procedural themes that were covered in the questionnaire.

Was genetics too difficult to understand?
Although the Jurors themselves spoke positively of their increase in knowledge after the Jury, one question put to observers was whether they thought that the topic of genetics was too difficult to be understood by a lay audience. Eighty-eight per cent of observers claimed that it was not too difficult, 8% were undecided and only 4% of observers thought the topic was too difficult for the Jury.

Many people attending the Jury were pleasantly surprised that participating in a Citizens’ Jury could have such a positive impact on people. One respondent found it ‘an interesting and valuable insight into informed public opinion’. The impact on the Jurors was also noted by a Welsh Office representative who attended on the first day: ‘I felt that the report demonstrated a significant increase in knowledge and a more informed view about the subject area on the part of the jurors’.
Some of the comments made on the topic of whether genetics is too difficult for lay people to understand included:

‘Professional people have a (very unfair) tendency to underestimate people’s capabilities.’

‘A lay audience might just need more time.’

‘The policy issues are not too difficult for anyone to understand.’

‘While their grasp of the technical terminology was not always good, the Jury seemed to be able to grasp social and ethical implications quite well.’

‘Lay audiences are always underestimated.’

‘I think we need to get past such patronising views - the specialists need to learn how to communicate their ideas ….’

How useful is a Citizens’ Jury as a method of public consultation?
Some respondents were unsure about how Citizens’ Juries related to other methods of public consultation. There was a general consensus that they should complement rather than compete with other methods. However there were varying opinions on how valid and reliable the recommendations of the Jury were. Comments received included:

‘It’s far better than just having interested parties slugging it out.’

‘An interesting development but it remains to be seen whether they prove useful.’

‘The decision reached by any one Jury should not be treated as if it came from a Court of Law. Several juries may need to discuss the same issue.’

‘A follow up should take place with the same Jurors to see if views have changed.’

‘A useful way to flag up issues and focus on the future.’

‘I wonder if a Citizens’ Jury comes up with any insights that could not have been arrived at by an informed focus group brainstorm.’

‘Only suited to a few issues of national importance.’

The limitations of the Citizens’ Jury method were recognised and the recommendations of the Jurors viewed in context. However, as many of the observers were already involved in decision making in some shape or form, it was often suggested that existing organisations and structures, e.g. social services, health authorities and trusts, should make use of Citizens’ Juries more often.

Commentators
Although many people responded informally to the Jury’s report or telephoned with comments, a small number of written responses were received from a variety of organisations. These responses ranged from brief letters acknowledging that the Jury had taken place and expressing thanks for the report, to approximately 20 detailed written analyses of the final report.
One English Community Health Council even sought advice on genetics before submitting their response so that they could contribute to what they perceived to be a very important debate. WIHSC was commended for tackling this difficult subject and, according to one organisation itself interested in the new genetics, for ‘involving members of the public in a way which supplements the many existing reports by expert committees’.

On balance it was generally agreed that the recommendations were clear and well thought through, e.g. ‘the recommendations are well expressed and cover a diversity of related subjects’ and ‘the report was well constructed and represented the findings clearly and constructively’. It was also stated that the recommendations ‘appear sensible and difficult to disagree with on the surface’.

One medical director of a Welsh Trust stated ‘My initial reaction was that a Citizens’ Jury would find it very difficult to reach a practical solution to the problem ... in this way. However, when I read the report I was very impressed by the whole process and the sound recommendations which the Jury had reached’.

Many respondents were pleased to see the Citizens’ Jury technique being used in Wales. The importance of public understanding and public involvement in decision making about genetics was constantly stressed, so that ordinary members of the public would have confidence in any future genetic testing services that are developed. On balance, almost all written responses received were positive about this process:

‘We believe that the Citizens’ Jury has provided valuable insights into the subject matter.’

‘I think the project is a substantial step forward in the process of decision making about controversial policies.’

‘The preparation by means of a focus group seems to have been excellent and we consider the test question to be relevant and appropriate.’

‘I was very impressed with the setting up of the Citizens’ Jury and the way that proceedings were carried out.’

‘The implications of new genetics require that the public has an understanding of the issues and are able to have confidence in any future genetic testing services that are developed. The Citizens’ Jury gives the lay populace the opportunity to make informed comments and recommendations.’

Generally there was consensus that Citizens’ Juries could be used as a technique for a wider range of health care issues, despite concerns about the financial and human resources costs. Respondents felt that the exercise was worthwhile and could be easily applied to other areas.

‘A Citizens’ Jury is a good way of gaining insight into public views on controversial subjects.’

‘I think that the exercise has been very worthwhile and could be well applied to other areas.’

Although everyone who responded to the Jury’s report criticised the process or the content of the recommendations in some way, it was generally felt that ‘criticisms ... will not over shadow our general support for this initiative’.
Some reservations were expressed about the Citizens’ Jury process in general, and these reflect the most common criticisms that are directed at Citizens’ Juries anyway, including the cost, the recruitment of Jurors, the selection of witnesses and wondering whether the Jurors really understand all the evidence. Of these criticisms the issue of cost is the one voiced most frequently. Typically Citizens’ Juries can cost between £16,000 and £20,000. The cost of this Citizens’ Jury was approximately £24,000 (excluding staff time), with much of the extra expense going towards the hotel venue and the use of CCTV for observers.

Many people - including the observers - felt that some issues had been overlooked or a witness perspective omitted. For example, it was suggested that there is no evidence [in the report] that there was any discussion of competing demands for time and resources in primary care. ‘The recommendations are a useful guideline for future services; however primary health care resources and commitment will be needed to achieve their full implementation.’

One criticism that came across quite strongly was the fact that there ought to have been a parallel Jury set up to consider what priorities should be given to genetic testing in relation to other demands being made on NHS budgets, e.g. why did they not ‘consider such things as the relative priority of genetic services and genetic testing against other conflicting demands for resources’. Although this fails to appreciate the time, money and organisation necessary to undertake such a study, it is an idea that would merit further exploration.

Many respondents who did not attend the event were surprised that the Jury did not come up with any recommendations in relation to the potential effects of genetic testing on insurance, employment and issues such as mortgages. One consultant claimed ‘I would have liked to know what issues were discussed by the Jury, but which did not end up as recommendations.’ Although the Jury did discuss these issues on the first day, they did so as part of a general brainstorming session about their concerns for genetic testing. They were not included as it was decided that they were not directly relevant to the question.

Another weakness of the Jury system is that ‘whilst it can decide what it would like to be done, it cannot actually will the means for it to be done’. It was widely felt that the process of holding Citizens’ Juries requires further evaluation, and also further examination of how best to channel the public views to decision makers.

Conclusions
The objectives of this Citizens’ Jury were (1) to enable ordinary members of the public to address the issues surrounding the new genetics and health care effectively and (2) to enable them to frame recommendations for policy makers in this area. On balance it can be concluded that this particular Citizens’ Jury was effective in meeting its objectives and conducting the exercise in an open and transparent fashion. There is no doubt that this Citizens’ Jury was a positive experience for all concerned. From the perspective of the Jurors, the witnesses and the moderator, the process was educational, informative and empowering. The Citizens’ Jury was also widely publicised in the media and arguably also had an impact on the countless numbers of people who listened to the radio and read newspaper reports as the event was taking place. This research (which includes the preparatory focus group with a further 70 ordinary members of the public) has also confirmed that the structure of lay thought and opinion about science and technology in general, and the new genetics in particular, is complex and sophisticated.

Finally, almost everyone who attended the Citizens’ Jury or read the Jurors’ report spoke positively about the exercise as a way of taking forward the debate about the new genetics and the debate
about improving public involvement in decision making about the new genetics. Although more work needs to be done in both these areas, the Citizens’ Jury on Genetic Testing for Common Disorders is a first step towards integrating the views of ordinary members of the public into the policy making process.

References
